HIV Disease Summary

Information as of September 30, 2004 (based on 2000 population of 6,080,485)

HIV - without AIDS to date:

327	New HIV cases from October 2003 thru September 2004	12-month incidence	5.38 cases/100,000
3,603	Total HIV-positive, alive and without AIDS on September 30, 2004	Point prevalence	59.26 cases/100,000

AIDS cases to date:

373	New AIDS cases from October 2003 thru September 2004	12-month incidence	6.13 cases/100,000
3,617	Total AIDS cases, alive on September 30, 2004	Point prevalence	59.49 cases/100,000
7,385	Total AIDS cases, cumulative (alive and dead)		

NOTE: Please read the following regarding the above statistics.

HIV and AIDS CASE RESIDENCY AND DE-DUPLICATION EFFORTS

Background: HIV and AIDS Case Reporting

All states and U.S. territories have some form of HIV/AIDS reporting that incorporates reporting by individual medical care providers and/or laboratories conducting HIV-related tests. This national effort enables public health surveillance staff to track the scope of the HIV and AIDS epidemic. It also allows the federal government to allocate funds equitably to the states for the care of people with HIV and AIDS who cannot pay for all or part of their treatment.

All states and areas have been reporting AIDS cases since 1986. Because of advances in treatment that have extended the time between HIV infection and a diagnosis of AIDS, states began instituting HIV reporting in 1985 as a way of understanding how the epidemic has changed and the progress of HIV disease. However, HIV case reporting is currently less standardized than AIDS case reporting. Some areas or states have only recently implemented HIV reporting, and this reporting is not consistent across all areas. Therefore, AIDS case reports (also called surveillance data) are considered the only nationally representative data source for the epidemic.

The Problem: Potential for Duplication

Because AIDS surveillance data are a snapshot of the number of persons living with AIDS in a particular state at a particular point in time, they may reflect when a person entered the state health care system with a diagnosis of AIDS but not where the person currently resides and is receiving care. For example, a person may be diagnosed with AIDS in Illinois, but move to Indiana where he or she may continue with treatment. If the person does not inform his or her Indiana provider of a previous diagnosis in Illinois, the Indiana provider will report the case to the local health department as a new diagnosis. The outcome of this reporting would be that both Indiana and Illinois would have the same person counted as a new AIDS case. This situation results in duplicate case reporting to the CDC.

In the example cited, the case should only be counted by Illinois; its duplication artificially adds an AIDS case for Indiana and subsequently inflates the cumulative U.S. data.

The potential for duplication has become more of an issue because of the mobility of our society and also because of the success of treatment for HIV and AIDS. Persons with HIV or AIDS may move for reasons related to their infection, for example, to be near family or friends, to seek social support services, to seek more knowledgeable physicians, to seek experimental drug programs, or because of inability to work due to HIV disease. With the advent and success of highly active antiretroviral therapy (HAART), those persons living relatively healthy lives may move for reasons unrelated to HIV or AIDS–to seek out new job opportunities or simply to fulfill a dream of living in a different place. This mobility increases the challenge of avoiding duplication in counting persons with AIDS across different jurisdictions throughout the U.S.

Duplication could be a problem because surveillance data are used to track the epidemic and for allocation of Ryan White CARE Act (RWCA) Title I and II and other treatment and care funds. The RWCA is a major source of federal funding for HIV/AIDS care for un- and under-insured people living with HIV and their families. Currently, the federal government allocates money based on the number of persons estimated to be living with AIDS in a particular state. These numbers are obtained from a formula that uses AIDS cases reported to CDC. For equitable distribution of these funds, it is imperative that people with AIDS are counted only once, based on their state of residency at diagnosis.

The potential for duplication has increased since HIV case reporting has been implemented. This has occurred because there are more records for the same person over time. For example, in many states, health care workers must report laboratory tests indicating possible HIV infection (HIV antibody tests, CD4 cell counts, and viral loads) to health departments. Each state's routine surveillance practices are intended to identify these repeat reports and make sure cases are counted only once. But, if states cannot find correct information on what state the person lived in at the time of his or her diagnosis of AIDS or HIV (not AIDS), a person can be counted more than once.

The Solution: De-duplication

To counter the potential problem of duplication, CDC initiated the Interstate Duplication Evaluation Project (IDEP) in 2002. This considerable effort compared patient records in the national database across states in order to identify potential duplicate cases. The following process was used.

1. CDC reviewed the national case reports sent to CDC through December 2001 for duplications. Because CDC does not receive names of patients, a match of information consisting of soundex (which is a code for the last name), date of birth, and gender identified potential duplications.
2. CDC provided states with a listing of all cases that were potential duplicates from other states. CDC also included additional supporting information such as diagnosis and death dates to assist states in their attempts to determine whether persons were the same or different individuals.
3. States contacted each other to compare their patient profiles along with additional information available at the state level that is not reported to CDC.
4. Based on their discussions, the states decided whether the cases represented the same person. If they did, the states determined the state of residency at the date of diagnosis.
5. The states forwarded these decisions to CDC, which returned them, after processing and quality control, to the states for updating their surveillance databases. CDC anticipates that all updates will be complete by December 2004.

Results of IDEP

The results to date of IDEP show that the number of duplications at the national level is no higher than expected. This indicates that surveillance practices to minimize duplications have been effective. However, duplications were identified through this process and de-duplication needs to occur.

After de-duplication, the numbers of cumulative diagnosed HIV and AIDS cases in individual states will most likely decrease, as will the overall national numbers. CDC estimates that the decreases on the national level will be less than 5% of the AIDS cases reported over the entire history of the HIV epidemic.

CDC and states will continue to address potential duplications through routine surveillance procedures like those followed in IDEP.

The 1982-2001 IDEP is being done in 2 phases. Phase 1 is the largest. Indiana will publish the results of Phase 1 IDEP in the mid-October Quarterly Report. Changes in both HIV and AIDS cases will be available on the county map. Phase 2 will be completed by the end of the year. Updates to the IDEP project are to continue quarterly.

If you have further questions, you may contact the HIV/AIDS Epidemiologist at 317-233-7506.